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# An Africa Without Autism

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Nana Nyama Danso has over four years' experience working with Civil Society Organisations (CSOs) that focus on entrepreneurship, gender issues and women empowerment. She is an advocate for women and children's well-being in West Africa specifically Ghana. She has interest in researching into maternal, child and adolescent health and changing perceptions of people on developmental disabilities. Nana Nyama believes in an equitable society where each individual has opportunities to become their best so they can affect society positively. She looks forward to working with and learning from development partners, other CSOs and stakeholders that work on the child marriage menace in Ghana and Africa. She believes collaborative efforts will help reduce the burden of child marriage on the young mother, child, society and nation as a whole.

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- To raise awareness on key issues in West Africa;
- To generate debates and discussions on these issues;
- To proffer recommendations on civil society involvement in advocacy;
- To provide recommendations to policy makers.



# **An Africa Without Autism**

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# World Autism Awareness Day

## INTRODUCTION

Globally, World Autism Awareness Day has been celebrated annually on April 2 since 2008 to raise awareness about the Autism Spectrum Disorder. The theme for the 2020 World Autism Awareness Day is 'The Transition to Adulthood'. Young people living with autism in transition from teens to adulthood face new challenges, needs, responsibilities and opportunities. The theme draws the attention of world leaders, governments, development agencies, health professionals, civil societies and citizens to this and also to propose solutions that will mitigate adulthood challenges for persons living with autism.

### 1 - What is Autism ?

Autism is a lifelong developmental disability<sup>1</sup> that affects how a child understands what they see, hear, how they relate to other people and make sense of their surroundings. It is a spectrum condition, which means that, while all people with autism share certain common difficulties, specific conditions are associated with individual autistic patients (Simons, 2014)<sup>2</sup>. They have limited language skills as such they find it difficult to initiate and sustain a conversation.

Autism is a disorder of the nervous system, present from birth and is evident before the age of three. It is incurable but manageable. Early interventions based on best practices help children to develop skills, learn to communicate effectively and enjoy family interaction (Ministry of Children and Family Development, 2013)<sup>3</sup>. All children with autism have in common three serious impairments, which include

their social interaction, their ability to communicate, and their patterns of behaviour.

Autism is assumed to have multiple causes, each of which may be manifested in different forms (Pierangelo & Giuliani, 2012)<sup>4</sup>. Most researchers agree that the collection of symptoms constituting Autism Spectrum Disorders (ASD) arise from a set of inherited factors including environmental and genetic factors. There are no specific medications for the treatment of autism.

### 2 - Statistics on Autism

Autism does not discriminate based on race, nationality, ethnicity or social status. Prevalence of ASD has increased over the years with global estimates being one in 160 children. However, reliable data on autism prevalence is difficult to come by in Africa. In South Africa, autism affects one in 158 children under the age of six (CDC, 2007)<sup>5</sup>. In a study by Seif Elden et al (2008)<sup>6</sup> which involved two North African countries (Tunisia and Egypt), ASD prevalence among children with developmental disabilities were 11.5 per cent and 33.6 per cent respectively.

In Ethiopia, the prevalence of autism is unknown, but prevalence studies of general mental health problems and intellectual disabilities indicate that these problems are at least as prevalent as in high-income countries<sup>7</sup>. In Ghana, the Ghana News Agency (2012)<sup>8</sup> reported that there were 400 ASD patients, out of which 90 per cent are boys aged two years. Although, reliable data is not available on the prevalence rate of autism in Africa, it can be inferred that autism prevalence is on the rise.

<sup>1</sup> Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.

<sup>2</sup> Simons, L. (2014). Think differently-act positively perception of autism. The National Autistic Society Accessed on 21 April 2015 from [https://www.google.com.gh/search?q=Simons%2C+L.++\(2014\)+Think+differently+act+positively+perception+of+autism.+The+National+Autistic+Society&rlz=1C1KMZB\\_enGH566GH567&oeq=Simons%2C+L.++\(2014\)+Think+differently+act+positively+perception+of+autism.+The+National+Autistic+Society&aqs=chrome..69j57l6j0j8&sourceid=chrome&es\\_sm=93&ie=UTF-8](https://www.google.com.gh/search?q=Simons%2C+L.++(2014)+Think+differently+act+positively+perception+of+autism.+The+National+Autistic+Society&rlz=1C1KMZB_enGH566GH567&oeq=Simons%2C+L.++(2014)+Think+differently+act+positively+perception+of+autism.+The+National+Autistic+Society&aqs=chrome..69j57l6j0j8&sourceid=chrome&es_sm=93&ie=UTF-8)

<sup>3</sup> Ministry of Children and Family Development (2013). A parents handbook: Your guide to autism programs. Accessed on 26 August 2015 [https://cdn.shopify.com/s/files/1/0219/5648/files/Parents\\_Handbook\\_-\\_BC.pdf](https://cdn.shopify.com/s/files/1/0219/5648/files/Parents_Handbook_-_BC.pdf)

<sup>4</sup> Pierangelo, R., and Giuliani, G. (2012). Teaching students with Autism Spectrum Disorder. A Step-by-Step Guide for Educators. (1st ed.) New York, NY Skyhorse Publishing House. ISBN-13: 978-1620872208, ISBN-10: 162087220X

<sup>5</sup> Centre for Disease Control and Prevention (2007). Prevalence of -Autism Spectrum Disorders- Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000. MMWR SS; 56(No.SS-1).

<sup>6</sup> Seif Eldin, A., Habib, D., Noufal, A., Farrag, S., Bazaid, K., Al-Sharbaty, M., Badr, H., Moussa, S., Essali, A., & Gaddour, N. (2008). Use of M-CHAT for a multinational screening of young children with autism in the Arab countries. Int Rev Psychiatry; 20(3): 281 - 289. [https://www.researchgate.net/publication/268143455\\_Services\\_for\\_Children\\_with\\_Autism\\_and\\_Their\\_Families\\_in\\_Ethiopia\\_Service\\_Providers'\\_Perspectives](https://www.researchgate.net/publication/268143455_Services_for_Children_with_Autism_and_Their_Families_in_Ethiopia_Service_Providers'_Perspectives)

<sup>7</sup> [https://www.researchgate.net/publication/268143455\\_Services\\_for\\_Children\\_with\\_Autism\\_and\\_Their\\_Families\\_in\\_Ethiopia\\_Service\\_Providers'\\_Perspectives](https://www.researchgate.net/publication/268143455_Services_for_Children_with_Autism_and_Their_Families_in_Ethiopia_Service_Providers'_Perspectives)

<sup>8</sup> Ghana News Agency. (2012, November 7). 'Autism specialist calls for more training of speech therapist. Retrieved on June 8, 2015 from <http://ghananewsagency.org/health/autism-specialist-calls-for-more-training-of-speech-therapist-51890>.



## I - PERCEPTION OF AUTISM

Autism is considered as a disability<sup>9</sup>. In many parts of Africa, culture, social status and religion have interacted and affected people's perception and attitude towards disability. All forms of disabilities are often considered as curses or punishments for sins committed either by the disabled, the family or one of his or her ancestors (UNDP, 2007)<sup>10</sup>. People with disabilities are treated with disdain in the society; and thus, suffer discrimination and exclusion from social, economic and political processes. The general treatment given to people with disabilities is that of pity and people deserving to receive alms from society (Slikker, 2009). On the contrary, they should be accepted and integrated into the society.

In most societies, autism (developmental disability) is perceived as a punishment for sin or wrongdoings. These beliefs have informed African society's attitudes towards families with an autistic child<sup>11</sup>.

Findings from a study in Nigeria by Igwe et al., (2011)<sup>12</sup> show a low level of knowledge and awareness about ASD. Like Nigeria, a similar perception holds in several other African countries. Low knowledge and acceptance of autism within the African continent has compromised early recognition of the disorder and intervention to alleviate symptom severity<sup>13</sup>.

<sup>9</sup> <https://www.therecoveryvillage.com/mental-health/autism/faq/is-autism-a-disability/#gref>

<sup>10</sup> UNDP, (2007). Ghana Human Development Report 2007: Towards a More Inclusive Society. Ghana Accessed on 20 July 2015 from [http://hdr.undp.org/sites/default/files/nhdr\\_2007\\_ghana.pdf](http://hdr.undp.org/sites/default/files/nhdr_2007_ghana.pdf)

<sup>11</sup> Cloete, L. G., & Obaigwa, E. O. (2019). Lived experiences of caregivers of children with autism spectrum disorder in Kenya. *African journal of disability*, 8, 435. <https://doi.org/10.4102/ajod.v8i0.435>

<sup>12</sup> Igwe, M. N., Ahanotu, A. C., Bakare, M. O., Achor, J. U., and Igwe, C. (2011). Assessment of knowledge about childhood autism among paediatric and psychiatric nurses in Ebonyi State, Nigeria; *Child Adolescent Psychiatry and Mental Health*. 5(1): 1.

<sup>13</sup> ibid

Inadequate knowledge and awareness about autism can lead to the negative attitudes towards autistic individuals and families. The negative implications of social associated with autism persist in today's society because of a lack of education concerning the syndrome.

Many people perceive these children as pampered children whilst the parents are either seen as persons who cannot control their children, or are considered as immature parents with stubborn children (Abdul-Rahman & Shamsudin, 2014)<sup>14</sup>. Society perceives the parents particularly 'the mother' as irresponsible.

A study by Danso (2019)<sup>15</sup> on 'Family Role in the Management of the Child with Autism: A Socio-cultural perspective in the Accra Metropolis' shows that different people perceive autism differently. Findings from the study show that 41 percent of the respondents indicated that autism is madness, 30.94 percent believed that autism is a form of spiritual curse and 9.35 percent think that autism is caused by a lack of parental care. Only 18.71 percent of the respondents thought autism is a developmental disability. Hence, it can be inferred that 81.29 percent of respondents hold a biased perception and a negative attitude towards persons living with autism. This therefore highlights the low level of understanding of ASD in the Accra Metropolis of Ghana. It partly also contributes to the marginalisation of persons with autism and their families and of course, the low level of acceptance by a society informed by the negative attitude towards persons with autism.

## 1 - Fears of Parents with an Autistic Child

A child is normally considered a blessing to parents, family and the society. It is the hope of parents that their child grows to a stage where they become independent, cater for themselves and start their own family. This apparently is the opposite for a child with autism who can rarely live an independent life. In their transition from childhood, puberty, teenage and adulthood, parents experience some challenges and fears.

As part of the study on 'Family role in the management of the child with autism: A Socio-cultural perspective

<sup>14</sup> Abdul-Rahman, S. S. B., and Shamsudin, S. B. M. (2014). A preliminary study: Awareness, knowledge and attitude of people towards children with Autism. *Social Science Research*

<sup>15</sup> Danso, N. N. (2019). Family role in the management of the child with autism. LAP LAMBERT Academic Publishing. ISBN-13: 978-613-9-96605-9



in the Accra Metropolis<sup>16</sup>, the researcher sought to study the fears and hopes of family members about the future of their children with autism. Using purposive and snowballing sampling techniques, 10 mothers and 3 fathers of children with autistic were interviewed at various educational institutes<sup>17</sup> for persons with developmental disabilities in the Accra Metropolis. With the help of school administrators, these parents voluntarily took part in the interviews.

In a 5 minutes interview, each parent was asked "how optimistic are you about your child's future? 7 mothers and all fathers expressed pessimism about their child's future. Their fears were mainly about the welfare of their children when they (mothers/ fathers) were not around.

One mother sighed and cried saying, "what will happen to him when I am not around (die)?" "Will people think he is mad and send him to a psychiatric hospital?" The other five mothers expressed similar sentiments; "what does the future hold for her", "will he be happy", "will he be protected or abused", "will there be someone to take good care of them", "will he just be like this", "will he be able to live in stigma without me". One mother expressed concerned about "service provision for autistics which was inadequate" in Ghana.

Mothers had peculiar fears for their daughters with autism. They wondered if their daughters will ever get married and have children of their own. Another mother had reservations about her ward's education (post- vocational/ Junior High School education) since there is a small entry for their educational progression.

However, some mothers were optimistic and had no fears for their child's future. One mentioned that, even though her daughter will not have a typical adulthood and go on to become a medical doctor or find herself in a university, she knows her daughter has capabilities which she will help her develop.

To show their commitment to their children, three mothers were practicing home care of their wards. With the availability of behavioural interventions

and training, they believed their children will be able to express themselves and do something for themselves. These findings corroborate the fears held by a mother of an autistic child in the United States of America who says; "what would happen to my boy when I am not around?"<sup>18</sup>

Even though it is challenging to take care of a child with autism, parents expressed high moments where their wards achieved milestones; for example, being able to communicate and take care of their own basic needs. For the low moments, most parents mentioned their ward's development regression and aggressive behaviours (meltdowns), which can cause grave injuries to themselves and others around.

## 2 - Steps to curtail these fears

Caring for children with autism should be a collective effort. Parents are at their wits' end especially in developing countries where the health systems are heavy-laden with multiple challenges and the society is the kind that marginalises people who look different from the normal.

Things that could be done to allay the fears of parents of children with autism include;

- **Government:** Through the Ministry of Gender and Social Protection and the Ministry of Health should interact with parents to find their specific needs and develop interventions that will meet these needs. Again, laws that guarantees the rights and privileges of people with special needs (inclusive education, freedom of association etc.) should be intensified and made known to the public.

- **Government and civil society organisations (CSOs):** They should spearhead a re-socialisation, re-integration effort where the public is educated on developmental disability and the need to accept all kinds of people. Society's acceptance of persons with autistic conditions will minimise fears of parents (abuse of children) when they are not around.

- **Civil Society Organisations:** CSOs should advocate for improved services for persons with autism. CSOs can run educational centres for persons with autism and advocate for government to design a curriculum that caters to people with autism to give them access to the job market and foster their integration

<sup>16</sup> Danso, N. N. (2019). Family role in the management of the child with autism. LAP LAMBERT Academic Publishing. ISBN-13: 978-613-9-96605-9

<sup>17</sup> The educational institutes included the Autism Awareness Care and Training Center, New Horizon and Awaa Waa 2.

<sup>18</sup> <https://www.healthline.com/health/autism/fears-of-autism-parent>

into mainstream society<sup>19</sup>. Access to these centres should not be restricted to well-educated and more affluent families. It should be opened to all, especially vulnerable families.

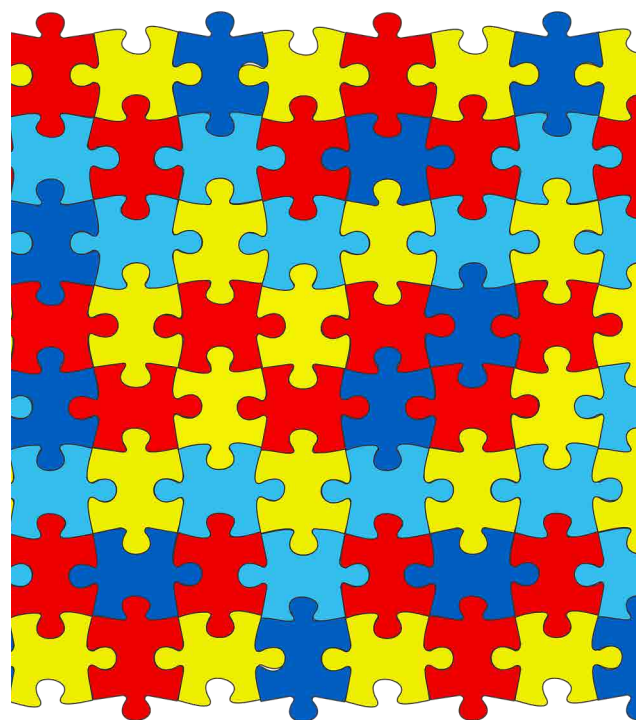
- **Improved provision of essential services for families and their children:** Improved essential services like diagnostic facilities, speech and sound assessments, psychiatric services, educational and therapeutic services should be provided for children with autism and families. These services should be extended to all regions in the country.

- **Support groups:** Support groups should be established in schools and community for parents with autistic children. They will serve as platforms where parents share their information, experiences and challenges. When parents know they are not alone in the journey, they will be comforted. These support groups can also be formed on social media platforms like WhatsApp, Facebook, etc. Extended family support is essential for parents at every stage of the child's development.

- **Private Sector support for autistic families:** The sector can support families by creating business opportunities for persons with autism who have peculiar skills and can work for a living. Again, the sector can establish homes for people with special needs. A home with infrastructure and expert staff, where children and adults with autism can live and be safeguarded and not pushed into psychiatric hospital when their parents are gone.

- **Citizens:** Citizens everywhere should interact and welcome others who are different. Through constant education, we must accept and appreciate people for who they are.

- **The need for more research and documentation:** A significant volume of documented knowledge and information about Autism is from the West. There is a need for research into autism in Africa taking into account the continent's complexity and uniqueness. Best practices over the years in managing persons with autism in Africa needs to be documented for future use.



## II- CASE IN POINT: PERSPECTIVE OF AN ADVOCATE FOR PEOPLE LIVING WITH AUTISM

Autism Awareness Care and Training Centre (AACT)<sup>20</sup> is a local support and educational centre for children with autism. The educational centre was established in 1998 by Mrs. Serwah Quaynor, a mother of a child with autism. The centre is committed to supporting individuals and families affected by Autism Spectrum Disorder (ASD). The centre believes that each child can use their God-given talent to reach their maximum potential, regardless of disability. They are dedicated to fostering meaningful education and independence for every child.

In an interview with the Executive Director of AACT, Mrs. Serwaa Quaynor mentioned her centre gives training and support to children with autism, their parents and family. They provide training and educational services to children with autism in order for them to function more effectively in society. The centre offers life-skills training, art and music therapy, respite care for families as well as education programs for caregivers.

There are periodic trainings and workshops offered to build capacity of teachers and careers to support children with autism. These teachers train families and

<sup>19</sup> Ndegwa, S (2019) Bringing hope to children with autism. African Renewal. <https://www.un.org/africarenewal/magazine/august-november-2019/bringing-hope-children-autism>

<sup>20</sup> Autism Awareness Care and Training Centre (AACT) is on 39 Royal Castle Road, Kokomlemle, Accra. The centre can be contacted on 030 222 4729, 024 432 5919. Email address is [aact@ghana.com](mailto:aact@ghana.com)

individuals to understand and get into the world of children with autism so they are well-able to accept and appreciate them. The centre helps persons with autism develop employable skills in beads making, art works and kente weaving.

As a mother of a child with autism (who is now an adult), Mrs. Quaynor affirmed there are uncertainties about the future of people with autism. Her centre undertakes a number of workshops and seminars to allay these fears of parents. They include one-on-one counselling, group counselling and periodic workshops.

In one of the workshops to empower parents, a group of lawyers spoke to parents about establishing a 'Trust Fund' or an 'Exit Plan' for their children with autism. The 'Trust Fund' or 'Exit Plan' gives parents the opportunity to provide their children a secured life when they are no more. It also makes available resources for their children and for parents to choose someone (a sibling or a family member) to care and protect their child in the future. She said siblings of a person with autism should know they have a responsibility to care for their sibling.

Parents must practically teach their other children all they need to know about their sibling's autism. They must be involved in their sibling's care or welfare, understand their sibling's autism and empathise with them since they are more likely to take care of them in the near future.

She mentioned that this year's theme 'The Transition to Adulthood' reveals a gap in the management of adults with autism since there are no systems in place to protect their future. Children with autism will not be children forever, it is expedient for parents to safeguard their future especially in Ghana and most African countries, where there are no homes and opportunities for adults with autism.



## CONCLUSION

Autism does not discriminate based on race, nationality, ethnicity or social status. As a lifelong developmental disability, its impact on families is completely overwhelming. Parents have fears about the future of their children with special needs.

In spite of the negative perceptions and low acceptability margins in Africa, it is also worth noting that there are some institutions, which have taken very positive measures to build capacity and support for such families. It is also important that parents put in place 'Trust Fund'/'Exit Plan' for their children to safeguard their safety and future. All stakeholders must work together to protect, empower and create an opportunity for children with autism to live their lives to the fullest.

Imagine a society where everyone is accepted. It is time we take a second look at the plight of people with autism and their families. We must strive to build systems and implement policies for persons with autism so their transition to adulthood is not fraught with challenges and uncertainties.



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